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TRANSPLANT SUPPORT ORGANIZATION

Serving Westchester, Putnam, Dutchess,
Bronx Counties and Southern Connecticut



VOL. 22, ISSUE 1

WINTER, 2017

Next Meeting Date

March 15, 2017

Greenburgh Health Center
295 Knollwood Road
White Plains, NY 10607

JULIA RIVERA



Our newsletter has featured a number of our members who have shared their personal stories of their path to transplantation. In this issue, we're bringing you the story of Julia Rivera, the soon-to-be retired Director of Communication at LiveOnNY. Julia's story is the same kind of inspiring message about her path to transplantation as a career.

Julia's career at LiveOnNY [formerly the New York Organ Donor Network - NYODN] began with a consulting assignment. Very quickly, however, NYODN figured out what they had and offered Julia a full-time job being "the voice" of the organization. This included her work to launch the "Dar Vida" program (Give Life) to raise awareness in the Hispanic community. Julia's comment about LiveOnNY is that "she was meant to be here all along."

Julia took advantage of her background and training and moved the NYODN into close contact with all of the minority communities. She called on her past activities to keep NYODN in the front of community interaction and press coverage. That background included her tenure as Director of Public Relations and Communications at Lincoln Hospital before she came to NYODN. At Lincoln, Julia participated first-hand in ethical activities that included organ donation. Lincoln Hospital, one NYC Health and Hospital Corporation's top Level 1 Trauma Center was a high donor hospital, so Julia came into contact with organ donation constantly. Prior to Lincoln Hospital, Julia had been the Executive Director of Aspira, a youth leadership organization.

Julia credits a great deal of success to her mother, supporters and mentors. She gives forward by being an active community leader and mentor, currently with a mentee from the Association of Hispanic Health Care Executives.

Julia intends that her retirement is equally as busy and fulfilling. Her children and grandchildren are very important to her, and her participation in her tenant's association and Loisaida - the Lower East Side neighborhood where she lives get her attention as well.

TSO is very grateful for Julia's participation in our relationship with LiveOnNY. We wish her well, we wish her good health, and we wish her happiness in her future.

Transplant Support Organization meetings are held at 7 p.m. on the third Wednesday of the month (with some exceptions) at
Greenburgh Health Center
295 Knollwood Road, White Plains, NY 10607

www.greenburghhealthcenter.com

Schedule for Monthly Meetings

7:00 p.m. — Social Time; 7:30-9:00 p.m.— Meeting and program for evening

Future Meeting Agenda

March 15 – Janet Ocasio - Member Journey from Illness Through Transplantation and Beyond

April 19 – Donate Life Month themed meeting

For directions to our meeting, donor registration form, and further information, please check our website: www.transplantsupport.org

To contact us by mail please write to:
TSO, 1335 Mace Avenue, Bronx, NY 10469
Or email us: email4tso@gmail.com

We are also on Facebook. Check us out for information and updates.
You do not need to have a Facebook account to visit TSO on Facebook .

To all recipients of this newsletter.
Please send your email address so we may notify you of any last minute changes to our meetings. If you have changed your address recently please let us know so we can update our records.
Please send all correspondence to: email4tso@gmail.com

The UNOS National Patient Waiting List

Candidates as of 02/17/2017

| | |
|----------------|--|
| 98,242 | patients waiting for a kidney transplant. |
| 14,360 | patients waiting for a liver transplant. |
| 943 | patients waiting for a pancreas transplant. |
| 1,743 | patients waiting for a kidney-pancreas transplant. |
| 275 | patients waiting for an intestine transplant. |
| 4,015 | patients waiting for a heart transplant. |
| 47 | patients waiting for a heart-lung transplant. |
| 1,387 | patients waiting for a lung transplant. |
| 118,357 | TOTAL PATIENTS |

Every 12 minutes a new name is added to the waiting list.

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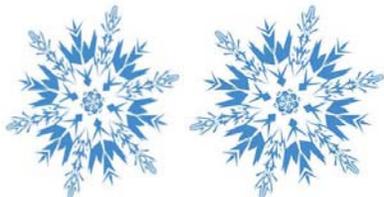
Co-Presidents' Corner - Winter, 2017

We all are aware of the challenges facing us in today's society. Political issues and legislative activities are several of the areas constantly in front of us in the news and in social media. And prescription drug coverage and medical costs add pressure to our lives.

It's refreshing, then, to be able to count on the day to day support of our friends and neighbors. We think this is exactly the kind of members we have in TSO. We can count on you to offer support, advice, and some good conversation whenever and wherever we meet together.

TSO intends to continue this tradition into the future. This is just a way of saying that we've been around for 20 years and we're planning to be around for many many more.

Stay tuned for our mail chimp and our email blasts as we carry on with our meetings and volunteer activities throughout 2017. And please plan to be with us again at our holiday party on Monday, December 4, 2017. It's not that far off on your calendars.



Ira Copperman and Gerard Marinaccio
Co-Presidents, TSO

TSO Meetings - November, 2016 through January, 2017

TSO continued its outstanding meeting program in the last part of 2016.

In November, **Jason Marinaccio** came to TSO talked to us about drugs and drug interactions for transplant recipients. Jason had also been at our September, 2016 meeting giving out flu shots.

December, 2016 was our annual **Holiday Party** at the Tarrytown DoubleTree Hilton. Thanks to all who came out that evening.

There wasn't a TSO meeting in January, 2017.

Please look out for our upcoming meeting program that starts in February, 2017.

Jessi-Ann Bettcher, Our Friend



TSO fondly remembers our friend Jessi-Ann Bettcher, who passed away on November 3, 2016. She was 27 years old.

Jessi-Ann and her mother were regular attendees at TSO meetings as Jessi-Ann recovered from her heart transplant. Then Jessi-Ann finished her studies and went on to start her own soccer management

business. Jessi-Ann had been a star soccer player even up to the time she needed a transplant.

Jessi-Ann was a featured player supporting organ, eye, and tissue donation as well. She appeared on posters and videos and was interviewed countless times about her experience.

Her spirit and zest for life will always be remembered.

TRIO-Manhattan Hosts “Rejoice & Remember”

TRIO-Manhattan, our support group friends from Manhattan, will host the 22nd anniversary of “Remember and Rejoice” at St. Patrick’s Cathedral on Saturday, April 22, 2017, starting at 2 p.m.

For those of you who have attended in past years, you will recall the uplifting messages of hope and thanks. For those of you for whom this will be the first time, here is your opportunity to offer thanks to donor families for the gift of transplantation. TRIO-Manhattan will again have an outstanding program.

For additional information, please contact Fran Dillon at 718-767-0800.

TSO Meetings February through April 2017

Our regularly scheduled meeting that took place on Wednesday, February 15, 2017, at Greenburgh Town Hall, had ***Phoebe Kmeck***, from LiveOnNY, who took us through LiveOnNY’s plans and programs for 2017.

Looking ahead to March 15, 2017, ***Janet Ocasio*** will share with us her journey from illness through transplantation and beyond. For those of you who haven’t heard our member stories, these are poignant meetings on personal stories of transplantation.

April, 2017 is ***Donate Life Month***. We will feature activities with social workers and staff nurses from the regional transplant centers. Additional details will follow.

TSO is always looking for new ideas for meetings. Please send in your suggestions to our meeting chair, ***Glenda Daggert***.

The Members' Corner

TSO is starting a section of our newsletter devoted to events and activities from our members.

Do you have a recent high school or college graduate?

Is there a new arrival in your family, a child or grandchild?

Have you recently returned from a great vacation or are you getting ready to start out on one?

Have you reached a milestone with your employment or recently been promoted or even started your retirement?

Have you started your own business or joined a new enterprise?

These are just several of the types of information we would enjoy hearing from you.

Send your stories to Carol Robinson, cjrobinson@optonline.net.

And just to get us started, we welcomed Jason Marinaccio, son of Madeline and Gerard, to talk to us in his role as a pharmacist. Jason is a PhD graduate in pharmacy and a practicing pharmacist. He told us about drugs and drug interactions important to transplant recipients.

TSO Board Meetings and Annual Meeting

TSO holds board meetings 4 times a year, in February, May, August, and November.

In May, we hold our annual meeting with the election of board members and officers. If you're interested in participating on the TSO Board, please give your name to any of our current board members. There are many opportunities for board members to give a few hours of time every quarter to keep TSO healthy and thriving. We welcome hearing from you.

If you have some ideas about volunteer activities in your community or speakers for our meetings, please let us know. We want TSO to be your support group.

Advertising TSO

We need your help to expand our mailing list and membership at TSO. Members come to meetings and support the speakers who come to talk with us. Members participate in our volunteer activities and registration events. And members help write letters and emails to legislatures and government departments to help everyone touched by transplantation.

We have several aids you can use that talk about TSO. First, we have our newsletter we publish four times a year. Our newsletter has information about our meetings and activities. Next, we have our website, www.transplantsupport.org. We also have our Facebook and Twitter social media sites. Then we offer our descriptive brochure that goes in waiting rooms and doctors' offices. That's the English language version. We're pleased to announce that we now have a Spanish language version of our brochure.

We encourage you to let people know about TSO. Please contact us to order any of our material.

Honor for Helen Irving

Helen Irving, President and CEO of LiveOnNY, was honored by the Queens Federation of Churches at its award dinner on Friday, January 27, 2017. Helen received the award for her outstanding leadership in Queens on behalf of organ, eye, and tissue donation.

TSO was honored to be at Helen's table at the awards dinner. Helen's group included Julia Rivera, Karen Cummings, and Megan Fackler, from Helen's staff; Margaret Valsecki, a donor mom; Dashia Macleod, on the waiting list for a heart; Glenda Daggert and Ike Copperman, transplant recipient and caregiver; and TinaMarie Sammon and her fiancé Glenn Mowbry, recipient and caregiver from TRIO-Manhattan.

By the way, we learned that Helen is a hiking enthusiast and mountain climber.

Our new Liaison at LiveOnNY

Megan Fackler has recently joined LiveOnNY for volunteer support and is LiveOnNY's representative to TSO.

Megan has Bachelor of Arts degree in Political Science and History from Iona College and over eight years of professional experience in the areas of public relations and intergovernmental affairs. She interned with US Senator Charles Schumer in 2007 and later served as the Communications Director for former Assemblyman Mike Spano. More recently, she served as the Coordinator of Government Relations at Time Warner Cable with a team focused in New York City and New Jersey. There she built, developed and leveraged relationships with elected officials to achieve Time Warner Cable's legislative goals and agenda while handling the compliance and regulatory needs of the company to City and State agencies.

She currently resides in Metuchen, NJ with her husband, Greg and 11 month of daughter Delaney.

Legislative Activities

February, 14, 2017 was a milestone in support of transplantation in New York State. This was the day that 16 to 18 year olds could enroll in the New York State Donor Registry through the driver's license and know that their wishes would continue uninterrupted on their 18th birthdays.

This was an important piece of legislation brought home by the New York Alliance for Donation, led by Aisha Tator, Executive Director. We are grateful to Aisha and the alliance for their patient pursuit of this law.

On the national front, there will be more information made available in the upcoming months as personnel changes are announced and confirmed at the various federal agencies. We will keep you posted on information we receive and action activities you may need to take concerning Part D prescription drugs and liver allocation proposals.

Organ Transplants Set Record in 2016

For the fourth year in a row, the number of transplants in the United States increased to record levels. And 2016 was no exception. More than 33000 transplants took place. That's more than 92 transplants every day across the United States. Please check out the link to the article written by Dr. Stuart Sweet, President of the OPTN/UNOS Board of Directors.

Certainly, there is more work to be done, more education to be given, more people in every state to be registered as organ donors. But it is gratifying to read that the message is loud and clear and is being received by so many people who then say yes to donation.

In our own New York State, there were more than 2100 transplants from more than 800 donors, living and deceased. So New York families are listening to this message as well. Your efforts on behalf of transplantation are succeeding. Thank you!

Dr. Sweet's full message is at the following link:

<https://www.unos.org/us-organ-transplants-set-record-in-2016/>

TSO's Service Area

TSO's meetings and activities are open to one and all. We welcome anyone who wants to participate.

In general, TSO's members come from the Westchester, Putnam, and Bronx vicinities. Just as all of the transplant support groups in the New York area cover a convenient geographic area, TSO strives to make it easy for people to attend its meetings and volunteer events.

The "New" TSO Website

Several members of TSO recently came together to revamp our website, making it more relevant and lively. We thank Gerard Marinaccio, Nancy Block, Helen Bellhouse, and Janet Ocasio for reviewing the website and improving its look and content. And we especially thank Rob Billman, who implemented all of the changes and added several of his own, as well.

Check us out at www.transplantsupport.org

And don't forget that we are still very active on Facebook.

You can find new articles and information almost every day.

Help Support TSO and Shop Using Amazon Smile



**New Amazon
Program Enables
Shoppers to Easily
Donate to Their
Favorite Nonprofits**

You can now help support TSO when you shop using Amazon Smile. It's simple – just sign in to www.smile.amazon.com and choose Transplant Support Organization Bronx, NY as the charity that you would like to support. The Amazon Smile Foundation will then donate 0.5% of all eligible purchases to TSO!

The Science Corner



Sixteen months after his groundbreaking and miraculous face transplant, Patrick Hardison continues to flourish. Patrick still comes to NYU Langone Medical Center every month for medical consultation with his surgeon, Dr. Eduardo Rodriguez. Dr. Rodriguez is a pioneer in face transplantation and created the program at Johns Hopkins before he came to NYU Langone.

Patrick was recently featured on the front cover of “News&Views”, the in-house magazine published by NYU Langone. His doctors at NYU credit his extraordinary recovery and success to his personal perseverance to exercise, methodical commitment to his immunosuppression medication, and follow-up

with his medical team. He can now chew without pain, close his eyes, and blink. With this ability, Patrick no longer has the risk of blindness.

In the time since this effort, NY Langone has expanded its programs in transplantation. Besides reconstructive and plastic surgeries, NYU now has services in liver, lung, kidney, and bone marrow. This comes as a result of a revamping of the transplant program. It is now called the NYU Langone Transplant Institute, headed by Dr. Robert Montgomery, who came from Johns Hopkins. Dr. Montgomery is complimented by Brigitte Sullivan, the Executive Director of the Institute, also from Johns Hopkins.

Note: This is the first in a periodic series of articles about the transplant centers and donor hospitals in the LiveOnNY Donor Service Area.

The TSO 2016 Holiday Party!



The DoubleTree Hilton in Tarrytown once again hosted TSO's annual Holiday Party. Friends, members, and guests gathered to help us celebrate this season's event.

TSO was honored with a table of guests from LiveOnNY. In addition, we hosted representatives from Northern Westchester Hospital. Caren Pennachio and Jennifer Lucas accepted an award to Joel Seligman and Northern Westchester for their outstanding community service on behalf of organ, eye, and tissue transplantation. Aisha Tator and Jeanne Shields from the New York Alliance for Donation also attended. TSO presented an award to Aisha and NYAD for their tireless efforts in raising the awareness and promoting donation in New York State.

In addition, TSO recognized Janet Ocasio, past president and constant board member, for her efforts to keep TSO's volunteer efforts in community events so active.

Finally, TSO recognized all of the volunteers who participated on organ donation awareness day on October 6, 2016. They helped LiveOnNY register the most number of people onto the registration list on a single day.



We thank everyone who attended and helped make our party such a festive event!



Happy Re-birthday to You!

Our best wishes to all our TSO friends and participants who celebrated re-birthdays in November, December, January and February! Our sincerest wishes for many more happy and healthy years to come!



Join TSO



Joining TSO is an important part of keeping us involved with you and with the entire transplant community. Our meetings, our events, and our legislative efforts come from your support.

Your dues allow TSO to continue doing the important work of education, support, public policy advocacy, and outreach which is so important to us all. Your dues are our main source of financial support. This is your organization, we need your dues to continue the work.

Please use the membership form found on page 11 to join and return the completed form with your check made payable to TSO.

If you have sent in your membership payment, thank you very much!
If you have not sent it in yet, please consider doing it today.





TSO Transplant Support Organization

Participant Application:

New

Renewal

Please fill out this form and mail it with your tax-deductible contribution to:
TSO, 1335 Mace Avenue, Bronx, NY 10469

NAME(s): _____

Mailing Address: _____

Phone # - Daytime: _____ Evening: _____ Cell: _____

Email: _____

PERSONAL INFORMATION (optional)

Birth Date: _____ Sex: _____ Marital Status: _____

Occupation: _____

CANDIDATE / RECIPIENT INFORMATION – Please check appropriate description

Donor _____ Donor Family Member _____ Transplant Recipient _____ Transplant Candidate _____

Family Member _____ Interested Individual _____ Professional _____

Have you already had a transplant? Yes _____ No _____

Type of Transplant(s) _____

Date of Transplant _____

Where did you (will you) have your transplant? _____

PARTICIPANT CATEGORIES & SUGGESTED CONTRIBUTIONS

Regular (Transplant recipient, transplant candidate, family member, donor family)

Individual Participant \$25.00

Family Participant (2 or more members, same address) \$35.00

Professional \$25.00

Please consider a voluntary donation to help support TSO \$ _____

TSO
Transplant Support Organization
1335 Mace Avenue
Bronx, NY 10469

NEXT MEETING: March 15, 2017

Transplant Support Organization's Mission

To help save lives by:

- ***Providing*** education relating to organ donation and transplantation;
- ***Promoting*** organ and tissue donation as an important social responsibility;
- ***Giving*** support to transplant candidates, recipients, their families and donor families;
- ***Effectively communicating*** to government bodies and the general public, the concerns and needs that affect the welfare of those individuals impacted by the transplant process.

